

Palliative Care

Background

The philosophy and models of palliative care that center on improving the quality of life for patients and their families grew out of approaches aimed at offering pain relief and comfort measures for adult and children cancer patients. Palliative care for HIV/AIDS includes interventions that respond to the physical, emotional, psychosocial, spiritual, and bereavement needs of adults and children with HIV/AIDS and their families; from the time of diagnosis, through final stages of disease and death. Although AIDS is an ultimately fatal disease, advances in care and treatment over the past two decades have extended life expectancy and improved quality of life for persons living with HIV disease such that earlier manifestations of the disease are now preventable or curable. The distinction between active, curative treatment and palliation is blurred. Current definitions of palliative care reflect a holistic approach that begins with the onset of disease and continues throughout the course of this chronic condition.

Palliative Care Definitions

In the year 2000, the World Health Organization (WHO) defined...*palliative care as an approach that improves the quality of life of patients and their families facing the problem associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual.*

It goes on to include earlier language from the 1987 definition. . . *Palliative care affirms life and regards dying as a normal process... neither hastens nor postpones death... provides relief from pain and other distressing symptoms... integrates the psychological and spiritual aspects of patient care... offers a support system to help patients live as actively as possible until death and to help the family cope during the patients illness and in their own bereavement... uses a team approach to address the needs of patients and their families, including bereavement counseling, if indicated...will enhance quality of life, and may also positively influence the course of illness...is applicable early in the course of illness, in conjunction with other therapies.*

The Health Resources and Services Administration (HRSA) has set forth the following working definition...*Palliative care is patient- and family-centered care. It optimizes quality of life by active anticipation, prevention, and treatment of suffering. It emphasizes use of an interdisciplinary team approach throughout the continuum of illness, placing critical importance on the building of respectful and trusting relationships. Palliative care addresses physical, intellectual, emotional, social, and spiritual needs. It facilitates patient autonomy, access to information, and choice.*

Building upon definitions of palliative care developed by HRSA and WHO; the President's Emergency Plan for AIDS Relief (the Emergency Plan) envisions expansion of an interdisciplinary approach to palliative care and support making use of interventions to relieve physical, emotional, and spiritual suffering. *Palliative care that includes basic health care and support, symptom management, and end-of-life care will involve the following elements: Routine clinical monitoring and management of HIV/AIDS*

complications...opportunistic infection prophylaxis and treatment...management of opportunistic cancers... management of neurological and other diseases associated with HIV/AIDS...Symptom diagnosis and relief...social support, including organization of basic necessities such as nutrition, financial assistance, legal aid, housing and permanency planning. End of life care that includes mental health care and support...social support ...support for care givers, and bereavement support for family members.

Palliative care, including end-of-life care, is an essential component of a comprehensive package of care for adults and children living with HIV/AIDS and their families. However, the range of services provided and the availability of caregivers varies by country and region. All definitions stress the fact that palliative care emphasizes the need for a team approach that will provide services all through the course of the disease and in various settings, e.g., in health care facilities, in the community, and in the home. In order to provide the broad range of palliative care services included in the most current definitions, effective linkages between health facility and community-based programs need to be established. This will contribute to establishing a continuum of care that capitalizes on the relative strengths and opportunities that each setting and personnel can offer.

As mentioned above, palliative care services may be provided in health facilities (e.g., central medical centers, district hospitals, public/private health centers, etc), or in the community. In the community, home-based care programs have been the typical venue through which palliative care services, including end-of-life care, reach the individual and the family. Although palliative care and home-based care sometimes have been used as synonyms, there are important differences to note. Palliative care is one of the services that a home-based care program can deliver. In the context of HIV/AIDS, home-based care programs may also serve to provide educational services, nutritional support and counseling, enhance follow-up and referrals, and more recently be used as a means to provide adherence support and to provide secondary prevention counseling.

Health systems in many African countries, Asia, and India are barely coping with the burden of acute diseases such as malaria, bacterial pneumonia, TB, and diarrheal diseases. Because of HIV infection itself, medical and nursing personnel are inadequate while medications and supplies may be in short supply. Shortages of medical personnel can be expected to worsen. Over 50 percent of beds on medical wards are occupied by HIV-infected patients in some countries where the Global AIDS Program (GAP) is providing assistance. Existing health infrastructures are inadequate to provide in-hospital care for AIDS patients resulting in pressure on hospital personnel to discharge patients quickly, often without treatment.

To cope with this crisis, many nations have encouraged "home-based care" (HBC) for persons with an HIV or AIDS diagnosis. Many programs have been developed, and some provide good models that ease suffering and improve quality of life. For example, the Chikankata Hospital program in Zambia provides both hospital care and an intensive program of follow-up in the community. The AIDS Support Organization (TASO) in Uganda has established eight day care centers that provide medical treatment, counseling, and food supplements for AIDS patients, plus a limited program of home care, and they have partnered with Hospice Africa.

Introduction of highly active antiretroviral therapy (HAART) has created new options for those infected with HIV. People receiving drug therapy will be coping with a chronic disease rather than a terminal disease. Palliative care in concert with curative therapies should be a goal for the standard of care for all HIV-infected persons.

Palliative Care Models

There are several programs providing palliative services that serve as models for providing palliative care. For example, Hospice Africa Uganda (HAU) has been described as a public health success. The government supports the organization and its program as a resource and training center for community and home-based care. HAU has successfully introduced oral morphine into the majority of government health units and trained clinicians on its use. Uganda is one of the few countries that includes palliative care as an integral part of the country's health plan. Various NGOs, including the AIDS Support Organization (TASO), provide counseling, care and support services, further increasing the reach of palliative care in underserved areas. Uganda's Partnership for Home-Based Care in Rural Areas, and the Mildmay Center for Palliative HIV/AIDS Care in Kampala have been cited in UNAIDS' Best Practice Collection.

The WHO Africa project on palliative care "A Community Health Approach to Palliative Care for HIV and Cancer Patients in Africa" is being developed in five of the countries in which the Global AIDS Program has programs. Each participating country--Botswana, Ethiopia, Tanzania, Uganda, and Zimbabwe--asked to develop and integrate palliative care initiatives into their national health care policies.

In the United States, the Ryan White Comprehensive AIDS Resources Emergency (CARE) Act, of the Health Resources and Services Administration's HIV/AIDS Bureau (HRSA/HAB), is a national program of the US Government which supports medical care and supportive services for underserved and resource-poor populations affected by HIV/AIDS. Several HRSA-funded programs are operating palliative care programs in the United States and its territories. Examples are the AIDS Services Center, an integrated care program providing patient centered care to disenfranchised patients suffering from HIV/AIDS in rural Alabama. The community-based hospice/palliative care center provides home and clinical-based hospice palliative care to HIV/AIDS patients, and maintains residence for a limited number of homeless clients. Estancia Corazon, Inc., a non-profit community-based organization located in Mayaguez, Puerto Rico provides care for medically indigent persons in the final stages of AIDS. These organizations operate in resource-poor areas similar to sites in Africa and Asia. Years of experience garnered through these programs can be useful lessons learned for developing countries. There are also Palliative Care Programs at the University of Maryland's Institute of Human Virology in Baltimore, the Montefiore Program in New York, and with Volunteers of America in selected city jails.

CDC Experiences and Capabilities

In close partnership with HRSA, a Global AIDS Program (GAP) goal is to provide, strengthen, and expand care and treatment services to people suffering from HIV/AIDS and opportunistic infections, building on the strengths of communities to provide options ranging from home-based care to clinical care and social support. Some countries that GAP works with, such as Uganda, South Africa, Kenya, Malawi, and Thailand, have

national AIDS plans that include protocols and support of palliative care and HHS/CDC (CDC) works closely with Ministries of Health to achieve host countries' goals. In other countries where there is no national palliative care policy, GAP works with partners, such as the US Agency for International Development (USAID), non-governmental organizations (NGOs), and community-based organizations (CBOs) to support areas in the continuum of care that includes palliative care, such as training lay health workers for home-based care and strengthening service coordination for persons living with AIDS. There are multiple faith-based clinics and home-based care providers throughout Africa providing in-home terminal care.

In collaboration with the Mildmay Center for Palliative HIV/AIDS Care, GAP Uganda provides technical and financial assistance for strengthening the capacity of health care workers in HIV/AIDS palliative care management, as well as training in the prevention and treatment of opportunistic infections. GAP Uganda is also working with Makerere University Department of Pediatrics, Makerere University Medical School to develop clinical guidelines and training curricula for pediatric HIV/AIDS care. In the past, CDC worked with Save the Children Fund UK (SCF-UK) to produce a Pediatric HIV/AIDS Handbook for Community care for use by community workers on children and families affected or infected by HIV. In partnership with TASO, the plan is to provide home-based care for the terminally ill clients using community-based medical workers, care givers, and TASO staff in an integrated set up.

GAP Thailand's palliative care focus is on improving the quality of life of children and families affected by HIV through strengthening the network of organizations that provide services by assessing and developing plans to strengthen current programs based on available data, and initiating death and dying counseling services in 3 provinces. This is a classic example of bereavement care being provided by hospice programs as an integral part of palliative care.

GAP Malawi is working closely with a hospital-based pediatric palliative care program to strengthen their program by developing guidelines and curriculum for the hospital's pediatric department.

GAP South Africa has provided technical assistance and support for the development of guidelines, training and training manuals for lay health workers to improve AIDS patient and family counseling, home-based care and coordination of community services for AIDS patients being discharged from hospital, which supports the MOH's "Step Down" hospital discharge program.

GAP Kenya has partnered with USAID to support the continuum of care for people living with AIDS by assisting with home-based care (through training) where needed to support other CDC activities.

Illustrative Activities

Local expertise, planning, participation, and guidance are central features of successful care and treatment infrastructures, including palliative care. The first step for instituting interventions for palliative care, including end-of-life care should be to recruit local experts to ensure their participation in all steps of the process. Following the buy-in of local participants, assessing current practices, resources, materials, and training opportunities

can help identify gaps. This assessment then leads to planning and implementing palliative care services. Throughout this process, patients, providers, funding sources (government and NGO), family, and community resources must all be included. The following activities are recommended:

- Assess existing programs (governmental and non-governmental organizations) in the countries providing palliative care to AIDS patients to identify current practices, resources and training needs.
- Establish and enhance linkages between hospitals, health units, and programs that provide palliative and end-of-life care to AIDS patients.
- Assist with efforts to inform, educate, and mobilize the community to promote community understanding and secure support.
- In collaboration with the MOH, NGOs, and donors, provide training to health providers, community health workers, community volunteers, and family members.
- Build capacity for long-term sustainability of palliative and end-of-life care.
- Using the WHO essential drug list in cooperation with the Hospice Palliative Care Association of South Africa, Hospice Africa in Uganda, and Mildmay Hospital, review and confirm the medications and supplies (analgesics, adjuvant drugs for analgesia and symptom control, antibiotics, antiretroviral drugs for prophylaxis, bandages, soap, alcohol, etc.) needed for optimum palliative care delivery. This may require providing infrastructure support such as storage facilities and technical assistance to procure, distribute, and maintain a steady supply of drugs and supplies. This might also include a “minimum care package” to be used by family members and community workers.
- In collaboration with WHO, UNAIDS and other collaborators, identify donors to procure the drugs and supplies needed for palliative care.
- Assess various models for providing palliative care, including end-of-life care to AIDS patients in developing countries to identify best practices criteria and develop guidelines.

Operational and Technical Considerations

According to the HRSA publication, *A Clinical Guide to Supportive & Palliative Care for HIV/AIDS, 2003 edition*, a national public health approach to palliative care is a first step for ensuring success. WHO endorses a national program strategy that requires an initial three-part process for improving palliative care. The foundation measures for this public health approach are: *Governmental policy: adoption of a national palliative care policy... Education: training of health care professional and the public... Drug availability: assuring availability of drugs for pain control, symptom management, and for prevention and treatment of OIs.* The President’s Emergency Plan for AIDS Relief will work with local regulatory authorities to remove barriers to opioids and other analgesics to treat pain and mitigate other symptoms. Specific activities may include: *implementation of policies to expand the use of oral opioids... liberalization of laws restricting medicinal use of opioids... expanding the ability of nurses to dispense pain medication, including opioids, and especially in the home setting... strengthening of laws to prevent diversion of opioids for illicit purposes.*

Operational and technical strategies for building long-term sustainability for palliative care, including end-of-life care involve the following elements:

- Provide technical assistance for development of appropriate supportive care protocols throughout the trajectory of illness including the end of life;
- Support and strengthen home-based care;
- Change curricula in health professional schools to reflect need for relief of suffering and necessity of an interdisciplinary team for care delivery;
- Increase links between HIV prevention and care programs near the end of life;
- Expand and integrate hospice services;
- Promote consideration and offering of pain control; nutritional support; prevention/treatment of OIs; and medical treatment for symptom management;
- Promote alternative and traditional health approaches where appropriate;
- Provide psychosocial and spiritual counseling support;
- Reduce stigma and discrimination of PLWA;
- Strengthen the ability of families and communities to care for vulnerable children, including orphans, in recognition of the major impact on this group by grief and bereavement;
- Expand voluntary HIV counseling and testing first in areas where antiretroviral therapy is being introduced;
- Identify new public-private partnership opportunities;
- Provide essential supplies including medications, nutrition, and physical aides needed for providing comfort; and
- Respect and honor local culture and spirituality.

Resources

Palliative care financial and human resources should be allocated within national AIDS programs as part of the continuum of care. It is important to stress that these programs should avoid viewing palliative care and disease-specific therapies as competing program areas. The more modern and ethically appropriate approach is to view active disease-specific therapies and palliative care as a part of a continuum in which patient needs and available resources determine the prioritization and balanced use of care strategies. Attention should be given to how the available resources can be fairly distributed to the largest population in a cost-effective and efficient system of healthcare delivery. Necessary resources should cut across the spectrum – human resources, (including training), financial resources, and material resources, e.g., medications, supplies, and nutrition. Donor resources should support national efforts whenever possible. The Department of Health and Human Services' Health Resources and Services Administration (HRSA), the Centers for Disease Control and Prevention (CDC) and their academically-based partners provide expertise for training and other cross-cutting activities that strengthen existing infrastructure for the delivery of palliative care. It is anticipated that the President's Emergency Plan for AIDS Relief will provide resources to implement basic supplies and medication for palliative care to meet its goal of providing care for 10 million HIV-infected persons and orphans.

Key Partners:

- Health Resources and Services Administration HIV/AIDS Bureau (HRSA/HAB)
- International Training and Education Center on HIV (I-TECH)
- University Technical Assistance Projects (UTAP)
- The US Agency for International Development (USAID)
- The Joint United Nations Program on HIV/AIDS (UNAIDS)

- The World Health Organization (WHO)
- Ministry of Health, non-governmental organizations, faith base organizations, persons living with HIV/AIDS, local experts and other community resources.
- Private industry (i.e. pharmaceutical companies...activities similar to the ones that provide drugs for HIV needs to be developed with pharmaceutical companies to make drugs available to patients for palliative care).

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Suggested Readings

"A Clinical Guide to Supportive and Palliative Care for HIV/AIDS," offers authoritative guidelines and practical, experience-based advice. This guide urges clinicians to treat not just the symptoms of this terrible disease, but to provide care that meets the physical, emotional, and spiritual needs of the individual. The clinical guide is available at the Health Resources and Services Administration's HIV/AIDS Bureau Website: <http://hab.hrsa.gov/>. An African version is being written at this time and will be published later this year being developed by HRSA and NHPCO.

U.S. Department of State (2004). "Critical Interventions in the Focus Countries: Care". Retrieved: March 25, 2004, <http://www.state.gov/s/gac/rl/or/29728.htm>.

"Palliative Care for HIV/AIDS in Less Developed Countries," (1998). Unites States Agency for International Development (USAID) discussion paper provides a preliminary review of some of the current thinking and research on palliative care. This document is available at USAID; The Synergy Project Website: www.synergyaids.com.

"A Community Health Approach to Palliative Care for HIV and Cancer Patients in Africa" is a World Health Organization (WHO) project in five countries – Botswana, Ethiopia, Tanzania, Uganda, and Zimbabwe to improve the quality of life for HIV/AIDS and cancer patients. A description of the project is available at the following Website: www.who.int/cancer/palliative/projectproposal.